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FAMILY SUPPORT AND RESOURCES OF FAMILIES OF CHILDREN WITH INTELLECTUAL DISABILITY AND AUTISM*

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Introduction: *Families with a child with intellectual developmental disabilities face fear, inappropriate information, ignorance, shame and exclusion. These circumstances lead to social exclusion of these families which makes their integration in the community even more difficult. The underlying reasons for bad status of families of children with intellectual developmental disabilities are deeply rooted in the social, economic, cultural and psychological foundations in all cultures. These families are in constant social isolation, and poverty and social exclusion are among the most relative features of the life of these families. Many of them live in an environment of discrimination, prejudices, ignorance, misinformation and unsatisfied basic needs. Very often these families are families with low incomes, and the reasons for poverty and social exclusion are the low employment rate, the unavailability of the public services and institutions, the lack of support they should receive by the community, as well as the insufficient development of the support services for these families by the state.*

Method: *This research has been conducted on a sample of total 122 respondents, 60 parents of children with typical development and 62 parents of children with intellectual disability and autism. With the use of a Family Support Scale and a Family Resources Scale, the resources at the disposal of these families, the support they receive from other family members and the community, as well as their needs, have been reviewed. The data collected have been processed with the statistical program SPSS (Statistical Package for Social Sciences).*

Results and Conclusion: *The results lead to a conclusion that families of children with disabilities still do not have enough resources in the community and the institutions of the system do not offer them sufficient support in order*

* This paper is part of the research done in master thesis named “Семејна поддршка и ресурси на семејствата на децата со интелектуална попреченост и аутизам”.

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for them to be able to complete their obligations without any obstacles, and at the same time allowing a better quality of life for all family members.

Key words: *intellectual disability, autism, families, family support, family resources*

INTRODUCTION

Republic of North Macedonia still doesn't have an appropriately developed system of formal and informal social protection, and the system itself functions on an unsatisfactory level causing additional problems to the families of children with intellectual disability and autism. Emotional problems faced by parents are very frequent and present, such as frustration, depression, anxiety, fear for their own future and the future of their children. This further leads to a change in the family climate, decrease of tolerance level, increase of conflicts and the need to find the culprit for all the problems the family is facing. The relationship to other children is also changed, they receive more tasks and obligations with regards to their brother/sister with intellectual disability or autism, which results in a decreased amount of free time, decrease of social contacts with their peers, and even the appearance of jealousy and a feeling of lower value.

AIM

This research has been conducted in order to determine family resources and the family support of the families of children with intellectual disability and autism in the schools with resource centers and regular schools. The research answers the questions regarding the differences in the family resources and family support with families of different nationalities, material status, employment status and educational status of the parents, as well as the different levels of disabilities and whether there are differences in family resources and family support between the families of children with typical development and children with atypical development.

METHOD

Descriptive and comparative methods have been applied during the research. Surveys and content analysis were used as research techniques. During the research, two scales have been applied. The Family Support Scale (FSS; Dunst et al., 1988), composed of 18 questions related to the degree to which certain persons or services offer their support to the families. Also, for this group of respondents, a Social Resources Scale was used, consisting of 30 questions. The Family Support Scale assesses the family's use of assets needed to satisfy their needs. In addition, the respondents received a survey for collecting demographic information for the

parents themselves and their children. The Social Resources Scale (Dunst et al., 1988) is composed of a total of 30 questions which in terms of their content can be divided into five categories on the basis of the level of availability of resources to satisfy: (1) basic daily needs, (2) accommodation and infrastructure needs, (3) social protection needs, (4) personal and social needs and (5) recreation, amusement and pleasure needs.

For the needs of this research, a Family Support Scale processing the availability of support for the families and their social integration has been applied. The scale consists of 18 items of potential support grouped in five categories of support: informal, partner, social organizations, formal support and professional service providers. The scale is a five-level Lickert-type scale with a range from “not at all” to “exceptionally a lot”.

The Family Support Scale (Dunst et al., 1988) assesses the family strength, functioning, relationships and interaction. The scale is composed of 30 items hierarchically placed based on the needs where basic needs are put on the first place. This scale is also a five-level Lickert-type scale where 1 means “never”, and 5 means “almost always”.

In addition to families of children with intellectual disability and autism, parents of children with typical development were also included as a control group. Within both groups of respondents (families of children with intellectual disability and autism and children with typical development) there were 60 respondents from regular schools “Dituria”-Saraj and “Dimitar Pop Berovski”, and 62 respondents from the primary school with a resource center “Zlatan Sremec”, with a total number of respondents of 122.

The data collected have been processed with the use of the statistical program SPSS (Statistical Package for Social Sciences). The use of standard statistical procedures for testing the significance of the differences between the arithmetic means (t-test for independent samples, ANOVA and similar) is not the appropriate choice if the criteria variable (here it is the Social Support Scale) is based on data from Likert-type assessment scale. Likert-type scales are based on ordinal measurement level and do not imply normal distribution of received data and as such they do not meet the primary requirement for analysis through standard procedures such as t-test for independent samples and ANOVA. In such situations, a solution for optimal statistics analysis is a choice of some of the procedures within the scope of nonparametric statistical procedures, and in the case in question, it would be the Mann-Whitney U Test as an alternative to the t-test for independent samples and the Kruskal-Wallis Test as an alternative to ANOVA.

RESULTS AND DISCUSSION

In less than half (46.72%) of the respondent families both parents are employed, and in approximately every third family (46.72%) one of the parents is employed and the other one is unemployed. In every sixth respondent family (16.39%) both parents are unemployed. An interesting data is the fact that, although outside of the primary

description of the sample characteristics, 85% (17 out of 20) of the families with both unemployed parents belong to the group of children with developmental disabilities. The data is similar with regards to families with one employed parent, where 75.56% (34 out of 45) are coming from such families. Statistical verification with Chi-squared test indicates that the pointed out tendency is statistically significant ($\chi^2=17.471$, $df=2$, $p<.01$). Taking into consideration the need of all-day care and engagement in the raising and educating the majority of these children, we consider that this data can be explained as a consciously made choice by the parents.

In two out of three interviewed families there are more than one child (66.39%), and we have only one child in every third family (33.61%). Statistical cross-referencing with the health and educational status of the child calculated using the Chi-squared test, confirms the statistically confirmed tendency of this sample children with developmental disabilities to appear more rarely as only children in the family, in comparison with their peers with typical development ($\chi^2=16.154$, $df=1$, $p<.01$).

As sources (indicators) of the support from informal groups from the local community in the Social Support Scale the following groups are taken into consideration: group of parents, social groups (clubs) and religious communities. The support from the religious communities has been ranked the highest (2.29), followed by the level of support of parents group (2.12), and the support from various social groups i.e. clubs and similar was ranked the lowest (2.00). The total average is 2.14 and it is significantly lower in comparison with the other segments of the SSS questionnaire. Overall, this result also creates an expected image, in synergy with the standards and the customs of the traditional socio-cultural matrix within the country. Within the Social Support Scale (SSS), the following categories are carriers of the professional support in the institutions of the society: family doctor, patronage pediatrics service, school day-care centers, professionals – individuals from the social environment and the professional institutions within the social sphere. The respondents have ranked the highest the support they receive as a school day care centers (3.00), followed by the support provided by professionals – individuals (2.87) and the support of the family doctor (2.78), while the lowest scales belong to the support provided by professional institutions (2.55) and the patronage pediatrics services (2.11). The total average is solid 2.66 and as such it is lower only in comparison with the average of the support provided by family, while it is higher in comparison with the support provided by friends and the social groups from the local community.

The parents of children with atypical development rank lower all four indicators of this type of support, but the data tables indicate that only one statistically significant difference has been registered. It refers to the support provided by colleagues at work, and parents of children with atypical development rank lower the support received by the colleagues in comparison with the parents of children with typical development ($Z=-2.344$, $p<.05$). No statistically significant differences have been registered for the remaining three indicators, i.e. the value/ranking of the support provided by their own friends, their partner's friends and by other parents.

Parents of children with atypical development rank lower the support received in comparison with parents of children with typical development for two out of five social support sources included in this segment: the support provided by the patronage pediatrics services ($Z=-2.226$, $p<.05$) and the school day care center ($Z=-2.629$, $p<.01$). However, the parents of children with atypical development rank higher the support received by the professionals – individuals within the social sphere ($Z=-3.026$, $p<.01$). There are no registered statistically significant differences with the remaining two indicators of social support, i.e. the support provided by the family doctor and the professional institutions within the social sphere.

The differences between the families with different social and economic status are pretty small. The statistical verification with the nonparametric Kruskal-Wallis test confirms this impression, demonstrating that there is no statistically significant relation. In other words, there are no registered statistically significant differences regarding any of the four indicators i.e. the ranking of the support provided by their own friends, the friends of the partner, by other parents and colleagues at work.

There is a tendency parents of children with atypical development to rank lower all six indicators regarding the level of satisfaction of basic daily needs in comparison with the parents of children with typical development. In such conditions, the statistical calculation from the data table points out to statistically significant difference in five out of six possible indicators. Specifically, it refers to the availability of sufficient financial means for their family daily needs ($Z=-4.415$, $p<.01$), for clothes ($Z=-3.854$, $p<.01$), for heating purposes ($Z=-3.406$, $p<.01$), for daily water supply ($Z=-2.096$, $p<.05$), and for enough money for monthly utilities invoices ($Z=-3.294$, $p<.01$), and in all three cases parents of children with atypical development use a lower average grade. There is no registered statistically significant difference regarding the availability of food for at least two meals per day.

From the five segments of the SSS: the satisfaction of personal and social needs, there is a lower value of all the indicators by the parents of children with atypical development and there are five registered statistically significant differences out of possible eight. It refers to the availability of enough time to sleep ($Z=-2.056$, $p<.05$), enough time for the partner and the friends ($Z=-2.974$, $p<.01$), for a conversation partner ($Z=-4.645$, $p<.01$), enough time for casual hanging out ($Z=-3.649$, $p<.01$) and enough time for recreation and self-care ($Z=-3.351$, $p<.01$). There are no registered statistically significant differences for the remaining three indicators: enough time for themselves, the family and the children.

In accordance with the expectations, the families with both parents employed consistently rank higher all six indicators related to the satisfaction of their basic daily needs in comparison with the families with one employed parent or two unemployed parents. On the other hand, families with one employed parent tend to rank higher these indicators in comparison with families with two unemployed parents. The statistical verification using the Kruskal-Wallis test confirms these differences as statistically significant for all six indicators, i.e. the satisfaction of food-related needs ($H=24.861$, $df=2$, $p<.01$), money for family's daily needs ($H=18.623$, $df=2$, $p<.01$), clothes ($H=25.363$, $df=2$, $p<.01$), heating ($H=19.667$, $df=2$,

$p < .01$), regular fresh water supply ($H = 8.589$, $df = 2$, $p < .05$) and money for monthly utilities invoices ($H = 19.130$, $df = 2$, $p < .01$).

With regards to the last of the five SSS segments: the satisfaction of the needs related to recreation, amusement and pleasure, families with both parents employed consistently rank higher all five indicators related to the satisfaction of their needs for recreation, amusement and pleasure in comparison with the families with one employed parent or two unemployed parents. Again, families with one employed parent tend to rank higher these indicators in comparison with families with two unemployed parents. The statistical verification using a Kruskal-Wallis test calculation confirms these differences as statistically significant for all five indicators. These are the indicators: availability of sufficient funds for children's toys ($H = 22.432$, $df = 2$, $p < .01$), funds for personal daily needs ($H = 17.821$, $df = 2$, $p < .01$), funds for family parties ($H = 19.108$, $df = 2$, $p < .01$), funds for excursions in the area ($H = 19.534$, $df = 2$, $p < .01$) and funds for annual vacation ($H = 28.309$, $df = 2$, $p < .01$).

Parents of children with atypical development (intellectual disability and autism) perceive differently and value a good portion of the aspects of social support that they receive in comparison with the parents of children with typical development. There is a different perception of certain aspects of the social support they are receiving. Parents with different socio-economic status perceive and value differently certain aspects of the social support they receive. Parents with different educational status perceive and value differently the social support they receive. Parents of children with atypical development (intellectual disability and autism) perceive differently and value the level of availability of social resources at their disposal compared to parents of children with typical development. Different ethnicity, as well as socio-economic status of the family, also affects the level of satisfaction regarding the services provided in the community.

How successfully the families will handle the difficult situation depends upon the quality of their mutual relationships within the marriage, parents' health conditions, appropriate service and assistance provision models, i.e. the treatment of children and families from a health, pedagogic and social aspect. Social protection can be divided into formal and informal protection. Informal protection includes the resources linked to the family, friends, neighbors and other relatives. The number of informal protection systems is a significant factor for the stress decrease related to raising a child with intellectual disability and autism. Wider social network is associated with more successful adaptation and coping. Families with children with developmental disabilities very often have a smaller network of informal protection and that is the reason for their greater social isolation in comparison with other families. Families or friends may not be able to foresee or feel the time when parents need their help the most. Grandfathers and grandmothers may not accept the diagnosis or they may blame one of the parents, of course, most frequently the one that is not related to them. Friends may feel uncomfortable in the presence of the child or maybe they will not know what to say to comfort the parents, and as a result, most often they stay aside. Furthermore, we can add that there is a probability that the parents are ashamed of their child and the problems he/she has,

and they very rarely dare to leave their home. All of the abovementioned factors can lead to social isolation. As far as the formal protection is concerned, it is focused on the resources received by a professional collective, including the protection of the child and the family through providing an appropriate institutional and non-institutional support, economic exemptions and incentives. The family resources are of great importance for stress decrease. A family with better economic situation and better health of its family members can handle stress more successfully. More intelligent parents with higher education levels can better understand the stressful situation they are facing and can develop better problem solving skills. However, on the other side, these families have greater aspiration for their children and are under greater pressure due to the gap between what they wished for their child and the reality surrounding them.

CONCLUSION

From the data gathered during the research we can note that the partners receive the greatest support from their partner, i.e. spouse. Very often the child with intellectual disability or autism and the mutual fight with everyday problems contribute the parents of children with disabilities to establish an even closer relationship. Also, it is a very good indicator that the respondents in average value the most the support they receive in the form of an all-day stay at school, which is the main objective of the organized treatment of children with intellectual disability. They also value highly the support from the immediate family members, parents of the partner and their own parents. The support from the religious community is also highly valued, as well as the support from their own friends. On the other side, they value the least the support from the colleagues at work.

The family as a natural environment for development and welfare of the children should receive the protection and the assistance needed in order for the family to be able to fully take its responsibility in the community. Taking this into consideration, as recommendations from the research we can point out the need of:

Education of parents regarding their rights and obligations, the resources they can use and how those resources will affect the improvements of their everyday life. This refers in particular to the short working hours as a benefit that is used by a minimal number of parents.

Working of the expert team with all family members, engagement of other expert profiles that could help with the decrease of the deviant behaviors in the families, as well as development of prevention strategies for such deviances.

Stimulating the parents for overcoming the prejudices and the obstacles in the environment and their re-inclusion in social activities, expanding their network of friends and their activities aimed at the broader social context.

Psychological support and counseling (resolution of everyday problems and organizing the life of children with disabilities, recognition of skills and talents of the children, how to properly encourage and direct the development of a child with intellectual disability).

Health care support (informing the institutions and the services in the community which could be of assistance, counseling with family members about the importance of regular medical check-ups, organized lectures on health protection and similar activities).

Educational support (additional learning support, cooperation with schools and pre-school institutions, buying school accessories).

Psychosocial support (expanding the social network of the family, connecting the family with the services provided on a local level, inclusion of the parents and the children in free sports, recreational and cultural activities, mediation with other institutions that are part of the support network and will contribute to improve the quality of life of the families).

In the local community: educational system, health care institutions, social protection institution, local authorities, public services, sports and cultural organizations, different humanitarian organizations and citizens' associations. The support that they are offering should be intense, each family should have an associate who will always be available, present and together with the family, the children and all other relevant members, will continuously and consistently support the family in achieving the desired changes in the life of the family and the child.

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